doi: 10.1111/hex.12315

Patient engagement with research: European population register study

Christopher McKevitt PhD,* Nina Fudge PhD,† Siobhan Crichton MSc,‡ Yannick Bejot MD,§ Benoît Daubail MD,¶ Antonio Di Carlo MD,** Patricia Fearon MBChB,†† Peter Kolominsky-Rabas MD,‡‡ Anita Sheldenkar MSc,‡ Sophie Newbound MSc,§§ Charles DA Wolfe MD*
On behalf of the European Implementation Score (EIS) Collaborative Group

*Professor, †Research Fellow, ‡Research Associate, Division of Health and Social Care Research, King's College London, London, UK, §Senior Lecturer, ¶Research Fellow, Dijon Stroke Registry, University Hospital and Medical School of Dijon, University of Burgundy, Dijon, France, **Researcher, University of Florence & Institute of Neuroscience, National Research Council of Italy, Sesto Fiorentino (FI), Italy, ††Clinical Research Fellow, Academic Section of Geriatric Medicine, Royal Infirmary, Glasgow, UK, ‡‡Director, Interdisciplinary Centre for Health Technology Assessment (HTA) and Public Health, University of Erlangen-Nuremberg, Erlangen, Germany and §§Manager, NIHR Biomedical Research Centre at Guy's and St Thomas NHS Foundation Trust and King's College London, Guy's Hospital, London, UK

Correspondence
Christopher McKevitt
Division of Health and Social Care Research
King's College London
7th Floor Capital House
42 Weston Street
London SE1 3QD
UK
E-mail: christopher.mckevitt@kcl.ac.uk

Accepted for publication
9 November 2014

Keywords: involvement in research, research awareness, stroke, survey

Abstract

Background Lay involvement in implementation of research evidence into practice may include using research findings to guide individual care, as well as involvement in research processes and policy development. Little is known about the conditions required for such involvement.

Aim To assess stroke survivors' research awareness, use of research evidence in their own care and readiness to be involved in research processes.

Methods Cross sectional survey of stroke survivors participating in population-based stroke registers in six European centres.

Results The response rate was 74% (481/647). Reasons for participation in register research included responding to clinician request (56%) and to 'give something back' (19%); however, 20% were unaware that they were participating in a stroke register. Research awareness was generally low: 57% did not know the purpose of the register they had been recruited to; 73% reported not having received results from the register they took part in; 60% did not know about any research on stroke care. Few participants (7.6%) used research evidence during their consultations with a doctor. The 34% of participants who were interested in being involved in research were younger, more highly educated and already research aware.

Conclusions Across Europe, stroke survivors already participating in research appear ill informed about stroke research. Researchers, healthcare professionals and patient associations need to improve how research results are communicated to patient populations and

research participants, and to raise awareness of the relationship between research evidence and increased quality of care.

Introduction

Increasingly, patients are being repositioned as active partners in the production and maintenance of health, rather than as passive recipients of health care. This shift is apparent at a number of levels. Shared decision making and self-management promote the active engagement of patients in their own care.[1,2] Patient and public engagement in the development of health services development is promoted[3,4] and in some cases legally required.[5] Internationally, it has been recognized that citizens' and patients' participation and empowerment should be regarded as core values in all health-related work.[6] In the United Kingdom, research funding bodies require scientists to involve patients/public in research processes, including research prioritization and the development, conduct and dissemination of studies.[7] There are also calls for greater participation in the quality assurance through the design of quality and safety strategies[8] and implementation of evidence into practice.[9]

This paper arises from our interest in the latter, well-known problem: the need to improve the processes by which research evidence is translated into routine practice.[10–12] It has been argued improving implementation requires multifaceted approaches rather than addressing a single professional group[11] or employing a single strategy alone.[13] Whole systems approaches to implementation have been advocated that would include the participation of all stakeholders including healthcare organizations, professional bodies, patient groups and regulators.[14] Oliver *et al.*[9] have argued that lay people have a part to play in research implementation, as they have a 'vested interest' in ensuring that evidence based, effective care is delivered. They propose that lay involvement in implementation can take place at the level of individual patient consultations (where informed patients are encouraged to participate in decision making) but also through lay representative involvement in healthcare policy and practice.

However, few studies have investigated how patients are, or might be, involved in implementation work. In this paper, we report findings from a European survey that sought to investigate the potential of stroke survivors to be involved in service quality improvement through implementation of research evidence.

Study context: the European Implementation Score project

The European Implementation Score (EIS) project funded by the European Commission under the 7th Framework programme (FP7 223153) aimed to develop a method to assess how well research evidence is being implemented into practice in primary, secondary and specialist stroke care settings across Europe.[15] The project considered implementation from the perspectives of different groups including health and social care professionals, service managers, policy makers, stroke patient organizations and patients. Study partners all had long-standing experience in stroke service delivery and research, responsible for running population-based research registers to investigate stroke epidemiology and outcomes and national audits of acute stroke services for quality surveillance.

Stroke provided a useful case through which to study the question of implementation of evidence into practice. It is a common disease and a leading cause of mortality and adult disability worldwide.[16] Although stroke can occur at any age, risk increases considerably with age, and for many years, it was considered a disease of ageing. This accounts, in part, for the historical view that medicine had little to offer those with stroke: in the past, stroke care has been variously described as an inconvenience,[17] peripheral,[18] and a neglected or 'Cinderella' service.[19] However, in recent decades, there has

been a remarkable growth in stroke-related research, with the development of an evidence base of effective medical treatments for acute stroke and, to a lesser extent, effective rehabilitation interventions. For example, there is evidence of improved outcomes for organized multidisciplinary stroke care (stroke units),[20] early supported discharge[21] and thrombolysis for ischaemic stroke.[22] Nevertheless, there is also evidence that implementation of such evidence based treatments has been slow and unevenly achieved with national and international variations in practice.[23,24]

One EIS work package concerned the role of stroke survivors, carers and patient groups in implementation processes. It became clear in initial planning meetings that investigators had different understandings of the role of 'lay' people in implementation and that most did not share the UK investigators' understandings of patient involvement. Nor did they believe that their local stroke populations would regard themselves as having a role to play in research processes or implementation.

Our survey therefore aimed to investigate stroke survivors' research awareness, use of research evidence in their own medical care and willingness to be involved in research processes.

Methods

Setting

The survey was conducted with four European population stroke registers: the Dijon Stroke Registry, the Erlangen Stroke Project, the Sesto Fiorentino Study and the South London Stroke Register; one hospital based register – the Glasgow Stroke Register; and RIKS-Stroke, a register of stroke patients in Sweden primarily used for audit purposes. Information about these registers is provided in Appendix S1.

Questionnaire design

As we could find no existing questionnaire appropriate to our research aim, we designed the 'Your Say in Stroke Research' questionnaire, using a combination of questions from an existing questionnaire and newly devised questions developed in conjunction with stroke survivors.[25] Relevant questions from the US National Business Group on Health Online Survey were adapted and incorporated into the 'Your Say in Stroke Research' questionnaire.[25] These were questions related to consumers' use of research evidence to manage chronic conditions and make decisions about health care and treatments.

Over three sessions, researchers and four stroke survivors, members of an existing stroke patient research group, discussed the concept of research implementation to identify domains to be included in a questionnaire and then developed new questions for each domain or adapted existing questions for inclusion in the appropriate domain.

Preliminary versions of the questionnaire were tested and reviewed by 20 members of the stroke patient research group and three participants from the South London Stroke Register using a hybrid method of respondent debriefing and group discussions.[26] Any questions found to be ambiguous in the pretesting stage were rewritten based on advice from participants who had tested the questionnaire. The questionnaire was also reviewed by researchers from the five other stroke registers to ensure questions would be relevant to and answerable by participants from their registers. The questionnaire was discussed and modified at a meeting of register leads.

The final questionnaire included 14 closed questions covering the following domains: attitudes towards taking part in research; knowledge and use of research evidence and clinical guidelines; willingness to be involved in research processes. Participants' demographic and outcome data were available from the register in which they were taking part.

The same questionnaire was used for all register samples, but the original version of the questionnaire, developed in English, was translated (and back translated) into French,

German Italian and Swedish for use with the Dijon, Erlangen, Sesto Fiorentino and Riks-Stroke registries respectively.

Survey method

For four of the registers (The Dijon Stroke Registry, ESPro, Sesto Fiorentino Registry and the SLSR), administration of the questionnaire followed the same procedure. Participants eligible to participate in the survey were those who were 1 year post-stroke in 2011. They were asked to complete the Your Say in Stroke Research questionnaire as part of their routine annual follow-up. Depending on the systems in place for each register (See Appendices S1), completion of the questionnaire was undertaken by a fieldworker in a face-to-face interview, by telephone or by post.

For the Glasgow and Riks-Stroke registers, which do not routinely collect data at 1 year after stroke, register participants were contacted and asked to complete the 'Your Say in Stroke Research' questionnaire. In the case of Glasgow participants, participants who were 1 year post-stroke in 2011 completed a questionnaire in the outpatients' clinic. In the case of Riks-Stroke, 250 participants who had had a stroke within the 12–24 months prior to March 2012 were sent a copy of the questionnaire by post from the Riks-Stroke secretariat. It was not possible for this centre to collect individual socio-demographic data. Respondents were asked to complete the questionnaires without the assistance of next-of-kin and to send back the completed form to Riks-Stroke. There were no follow-up reminders for those who did not return the questionnaire.

Variable definition

Data were entered by each register and then transferred to Excel or SPSS files and sent to study principal investigators where the data sets were combined and cleaned for analysis.

Socio-demographic data (age at stroke; gender; ethnicity; living circumstances; and education) were available for all respondents from England, France, Germany, Italy and Scotland but not for respondents from Sweden. Respondents' level of disability was measured using their latest recorded Barthel Index (BI) or Modified Rankin Score (mRS), standard outcome measures used in stroke research. Using a validated procedure,[27] these outcomes were used to categorize respondents as independent (BI = 20, MRS = 0), having mild disability (BI = 15–19, MRS = 1–3) or having moderate/severe disability (BI < 15, MRS 4–5). Cognitive status at follow-up was measured using either the Abbreviated Mental Test (AMT) or the Mini Mental State Exam (MMSE). Respondents were defined as being cognitively impaired if they had an AMT score <8 or a MMSE score <24.[28,29]

Statistical analysis

Categorical data were summarized as frequencies and percentages, and the Chi-squared or Fisher's exact tests were used to make comparisons between groups, where appropriate.

The characteristics of participants in the five registers providing demographic data were summarized within, and compared across, countries. A comparison of age, gender and disability level of all responders and non-responders from these registers was also carried out.

As the age structure of the population of each of the countries included in the study differed, in univariate analyses responses from England, France, Italy, Germany and Scotland were weighted to provide age-adjusted estimates using the standard European population.[30] Weighted responses to each of the questions on the survey were summarized and compared across countries. No demographic data were available for respondents from Sweden; therefore, it was not possible to provide adjusted estimates, and these data are presented separately from the other countries.

Univariable comparisons were also made between the demographics and the responses to other items among participants who did and did not state that they would like to be involved in research.

Multivariable logistic regression models were used to assess associations between responses to questions (yes vs. no/don't know) and gender, age, disability and country. Unweighted data were used in the logistic regression analyses as the aim was to determine which participant characteristics, including age, were independently associated with response, rather than to make comparisons between countries. As age and country were both included as terms in the models, all estimates were adjusted for any differences in the age structure within each country. One item, on whether or not respondents had ever received results from the stroke registers, was excluded from multivariate analyses due to low numbers overall.

Analyses were conducted using Stata 12.0 MP and *P*-values <0.05 were considered statistically significant.

Ethics committee and research governance approval

Ethics committee approval for the survey was sought and obtained where necessary according to the requirements of each country participating in the survey. For the South London Stroke Register, a substantial amendment for ethical approval for the SLSR was granted from the National Research Ethics Service Committee London – Westminster (reference: EC01/020). For the Glasgow Stroke Register, ethical approval was provided by the West of Scotland Research Ethics Committee (REC ref. 11/WS/0028). For the Erlangen Register, Germany, ethics approval for the EIS project was granted through ESPro. For the Sesto Fiorentino Study, approval was granted by the Ethics Committee of the Careggi University Hospital. The Dijon Stroke Registry was approved by the National Ethics Committee.

Results

Response rate and respondents

Of 647 questionnaires distributed, 481 were returned, giving an overall response rate of 74%. Demographic data were available for respondents from all register samples except in Sweden (providing 189 of 481 responses).

Table 1 Respondent characteristics (excluding respondents from Sweden)

	Total	England	France	Germany	Italy	Scotland	*P* value
Number of respondents [response rate (%)]	292 (74.3)	70 (59.8)	81 (72.3)	50 (100)	66 (83.5)	25 (64.1)	
Age at time of stroke							
<65	101 (34.6)	29 (41.4)	30 (37.0)	14 (28.0)	19 (28.8)	9 (36.0)	0.501
65–74	76 (26.0)	17 (24.3)	16 (19.8)	18 (36.0)	20 (30.3)	5 (20.0)	
75+	115 (39.4)	24 (34.3)	35 (43.2)	18 (36.0)	27 (40.9)	11 (44.0)	
Gender							
Male	145 (49.7)	30 (42.9)	37 (45.7)	32 (64.0)	38 (57.6)	8 (32.0)	0.030
Female	147 (50.3)	40 (57.1)	44 (54.3)	18 (36.0)	28 (42.4)	17 (68.0)	
Disability							
Independent in activities of daily living	131 (46.3)	29 (47.5)	16 (19.8)	34 (68.0)	45 (68.2)	7 (28.0)	<0.001
Mild disability	120 (42.4)	19 (31.2)	62 (76.5)	16 (32)	8 (12.1)	15 (60.0)	
Moderate/severe disability	32 (11.3)	13 (21.3)	3 (3.7)	0 (0.0)	13 (19.7)	3 (12.0)	
Cognitive impairment[β]							
Impaired	28 (20.1)	9 (33.3)	–	2 (4.0)	17 (27.4)	–	0.001
Intact	111 (79.9)	18 (66.7)	–	48 (96.0)	45 (72.6)	–	
Education							
None	5 (2.9)	1 (1.6)	–	1 (2.3)	3 (4.8)	–	<0.001
Primary	47 (27.6)	7 (10.9)	–	14 (31.8)	26 (41.9)	–	
Secondary	105 (61.8)	46 (71.9)	–	29 (65.9)	30 (48.4)	–	
Higher Education	13 (7.7)	10 (14.7)	–	0 (0.0)	3 (4.8)	–	

Table 2 Unweighted (including Sweden) and weighted responses by country

	Number of respondents (%)		Number of respondents (weighted %)						
	Total	Sweden	Subtotal	England	France	Germany	Italy	Scotland	*P*-value
Why are you taking part in the stroke register?									
A clinician asked me to	216 (44.9)	54 (28.6)	162 (56.3)	19 (27.9)	59 (73.2)	34 (69.3)	38 (57.1)	12 (53.0)	<0.001
To access health and social care services	63 (13.1)	34 (18.0)	29 (6.6)	7 (9.4)	14 (19.4)	5 (11.3)	0	3 (8.0)	0.001
To give something back	184 (38.3)	121 (64.0)	63 (19.6)	19 (28.7)	12 (11.1)	17 (35.6)	5 (9.2)	10 (40.4)	<0.001
Encouraged to by a stroke patient organization	39 (13.4)	–	39 (7.9)	11 (16.9)	22 (25.2)	5 (9.1)	0	1 (3.3)	<0.001
Don't know	32 (6.7)	9 (4.8)	23 (9.2)	12 (16.8)	0	4 (6.6)	7 (11.3)	0	<0.001
Was not aware I was taking part in a stroke register	78 (16.2)	25 (13.2)	53 (18.4)	13 (15.5)	10 (12.8)	3 (4.4)	18 (25.2)	9 (29.8)	0.002
Are the questions the stroke register asks you relevant to you?									
Yes	287 (60.5)	99 (53.2)	188 (64.6)	42 (64.9)	60 (76.8)	26 (50.2)	46 (67.3)	14 (62.4)	0.013*
No/Don't know	187 (39.5)	87 (46.8)	100 (35.4)	25 (35.1)	21 (23.2)	24 (49.8)	20 (32.7)	10 (37.6)	
Have you ever received research results from the stroke register?									
Yes	49 (10.2)	6 (3.2)	43 (9.3)	8 (12.0)	26 (29.1)	8 (14.6)	1 (1.9)	0	<0.001*
No/Don't know	432 (89.8)	183 (96.8)	249 (90.7)	82 (88.0)	55 (70.9)	42 (85.4)	65 (88.1)	25 (100)	
Have you had opportunities to learn about stroke research from health care professionals or researchers?									
Yes	163 (34.5)	46 (25.4)	117 (37.3)	15 (23.1)	58 (69.6)	11 (20.2)	26 (41.5)	7 (29.8)	<0.001*
No/Don't know	310 (65.5)	135 (74.6)	175 (62.7)	55 (76.9)	23 (30.4)	39 (79.8)	40 (48.5)	18 (70.2)	
Have you ever read or heard about results of any research on stroke patient care?									
Yes	184 (38.9)	72 (39.6)	112 (36.1)	7 (9.6)	54 (65.6)	16 (36.1)	21 (34.8)	14 (56.3)	<0.001
No	290 (61.2)	110 (60.4)	180 (63.9)	63 (90.4)	27 (34.4)	34 (63.9)	45 (65.2)	11 (43.7)	
During a visit to your doctor about your stroke have they ever told you about stroke research that has been done and what it shows about the best way to handle your medical care or treatment decisions?									
Yes	100 (21.3)	29 (15.8)	71 (24.0)	6 (10.2)	32 (33.7)	2 (4.2)	18 (29.3)	13 (58.3)	<0.001
No	370 (78.7)	154 (84.2)	216 (76.0)	59 (89.8)	49 (66.3)	48 (95.8)	48 (70.7)	12 (41.7)	
During a visit to your doctor have you ever brought information on stroke research you found on an Internet website to discuss with your doctor?									
Never	342 (72.0)	142 (77.2)	200 (77.6)	61 (87.3)	40 (51.8)	23 (54.4)	61 (92.1)	15 (66.9)	<0.001*
Yes, once	24 (5.1)	6 (3.3)	18 (4.8)	1 (2.3)	14 (17.8)	0	3 (4.7)	0	
Yes, more than once	20 (4.2)	4 (2.8)	16 (2.8)	0	13 (12.0)	3 (7.0)	0	0	
I don't use the Internet	89 (18.7)	32 (17.4)	57 (14.8)	7 (10.4)	14 (18.5)	24 (38.6)	2 (3.1)	10 (33.1)	
Have you ever read or heard about the stroke clinical guideline?									
Yes	127 (26.8)	47 (25.8)	80 (22.3)	8 (11.2)	49 (61.9)	4 (8.9)	11 (19.8)	8 (29.8)	<0.001
No	346 (73.2)	135 (74.2)	211 (77.7)	61 (88.8)	32 (38.1)	46 (91.1)	55 (80.2)	17 (70.2)	

Table 2. Continued.

	Number of respondents (%)		Number of respondents (weighted %)						
	Total	Sweden	Subtotal	England	France	Germany	Italy	Scotland	*P*-value
Would you personally be interested in taking on a role where you could influence/get involved with stroke research?									
Yes	164 (34.8)	45 (24.7)	119 (32.0)	17 (26.0)	64 (79.4)	13 (28.4)	13 (19.6)	12 (53.6)	<0.001
No	178 (37.7)	69 (37.9)	109 (38.3)	37 (51.4)	9 (12.1)	31 (60.5)	22 (31.9)	10 (37.8)	
Not sure	130 (27.5)	68 (37.4)	62 (29.7)	14 (22.6)	8 (8.5)	6 (11.1)	31 (48.5)	3 (8.6)	

*Comparisons made between respondents who answered 'yes' and those who answered no, don't know or can't remember.

Analysis of responses where demographic data were available suggested that there were no differences between responders and non-responders by gender ($P = 0.304$) or age (0.499). There were, however, differences between responders and non-responders by disability level ($P < 0.001$), with those who were independent more likely to complete a questionnaire compared to those with moderate to severe disability. Characteristics of responders are presented in Table 1.

Taking part in register research

Respondents were asked about their motivation for taking part in a stroke register, choosing as many options as applicable (Table 2). Using weighted data, the most frequently selected reason was in response to a clinician request (56.3%) followed by altruism (19.6%), encouragement from a patient association (7.9%) and desire to access additional services (6.6%). Almost 20% of respondents, however, stated that they were not aware that they were taking part in a stroke register.

For all centres, including Sweden, 62% of respondents indicated that they understood why their stroke register was undertaking research. There were significant variations by country, with highest proportions of respondents from Sweden, Scotland and England, and lowest proportions from Italy reporting that they understood why the register was undertaking research. Overall, 60% reported that the register questions were relevant to them, but 34% reported not knowing whether the questions were relevant to them.

Research awareness

We aimed to investigate levels and sources of research awareness, as well as use of evidence in respondents' own medical care. Most respondents reported that they had not received results from the register they were participating in (73.4% weighted). Respondents from France were more likely to answer that they had received the results of register research, with almost 30% answering yes to this question.

Over half of all respondents stated that they had not had opportunities to learn about stroke research from healthcare professionals or researchers. This finding was consistent across all countries with the exception of France where a higher percentage (70%) of respondents stated that they had had such opportunities to learn about stroke research.

Just over 60% of the total sample reported never having read or heard about the results of research on stroke care. However, there were significant differences between countries: 90% of respondents from England reported never having read or heard about the results of stroke research compared to 66% in France.

Across the total sample, 31% reported not looking for research about stroke, with significant differences between countries. In England and Scotland, over 40% of respondents had not looked for stroke research, whereas no respondents from France selected this option. When asked which sources were used to find out about the latest progress on stroke research, across the total sample, 28% identified newspapers and magazines, followed by

Table 3 Comparison of responses in those willing and unwilling to take part in research processes (unweighted)

	Unwilling	Willing	*P*-value
Why are you taking part in the stroke register?			
A clinician asked me to	116 (37.7)	99 (60.4)	<0.001
To access health and social care services	35 (11.4)	28 (17.1)	0.082
To give something back	122 (39.6)	56 (35.2)	0.244
Encouraged to by a stroke patient organization	13 (7.6)	26 (21.9)	<0.001
Don't know	26 (8.4)	5 (3.1)	0.024
Was not aware I was taking part in a stroke register	64 (20.8)	13 (7.9)	<0.001
Are the questions the stroke register asks you relevant to you?			
Yes	164 (53.9)	121 (74.2)	<0.001
No/Don't know	140 (46.1)	42 (25.8)	
Have you ever received research results from the stroke register?			
Yes	17 (5.5)	32 (19.5)	<0.001
No/Don't know	291 (94.5)	132 (80.5)	
Have you had opportunities to learn about stroke research from healthcare professionals or researchers?			
Yes	80 (26.6)	83 (50.6)	<0.001
No/Don't know	222 (73.4)	81 (49.4)	
Have you ever read or heard about results of any research on stroke patient care?			
Yes	97 (32.2)	87 (53.1)	<0.001
No	204 (67.8)	77 (47.0)	
During a visit to your doctor about your stroke have they ever told you about stroke research that has been done and what it shows about the best way to handle your medical care or treatment decisions?			
Yes	49 (16.1)	51 (31.7)	<0.001
No	255 (83.9)	110 (68.3)	
During a visit to your doctor have you ever brought information on *stroke research you found on an Internet website* to discuss with your doctor?			
Never	226 (74.1)	111 (68.1)	<0.001
Yes, once	8 (2.6)	16 (9.8)	
Yes, more than once	7 (2.3)	13 (8.0)	
I don't use the Internet	64 (21.0)	23 (14.1)	
Have you ever read or heard about the stroke clinical guideline?			
Yes	60 (19.7)	67 (40.9)	<0.001
No	245 (80.3)	97 (59.2)	

healthcare professionals (27%) and television (26%). The internet and friends and family were cited by 16 and 15%, respectively. Stroke patient organizations were identified by only 6%, as a source of research information, with some differences by country. Across all countries, healthcare professionals were identified as the most trustworthy sources of information about stroke research.

From respondents' perspectives, evidence appeared to feature little in their own clinical consultations. Three-quarters of the total sample reported never being told by their doctor about stroke research evidence during a consultation; 85 and 72% reported never having ever taken information about stroke research sourced, respectively, from newspapers or the internet to discuss with their doctor. While stroke clinical guidelines exist in all study centres, 78% of respondents were not aware of them.

Involvement in research processes

Asked to identify all those who should make decisions about research, 74% of respondents identified 'healthcare professionals', 62.6% identified 'scientists/researchers' and 33.5% included 'stroke patients'.

Of the total sample, 34% reported interest in influencing or becoming involved in stroke research processes, 37% were not interested and 27% were unsure. Those aged <65 years were

Table 4 Multivariable associations between response and age, gender, disability level and country

	Relevance of stroke register questions		Opportunities to learn from health professionals		Heard about research on patient care		Dr told you about stroke research		Brought info from internet to discuss with Dr.		Awareness of clinical guidelines		Interested in getting involved in research	
	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value
Age														
<65	1	0.781	1	<0.001	1	0.048	1	<0.001	1	<0.001	1	0.040	1	0.004
65–74	1.2 (0.6–2.4)		0.3 (0.1–0.8)		1.1 (0.5–2.3)		0.3 (0.2–0.8)		0.5 (0.2–1.5)		0.6 (0.3–1.4)		0.5 (0.2–1.0)	
75+	0.9 (0.5–1.8)		0.2 (0.1–0.5)		0.5 (0.3–1.0)		0.2 (0.1–0.5)		0.1 (0.0–0.4)		0.4 (0.2–0.8)		0.3 (0.1–0.6)	
Gender														
Male	1	0.984	1	0.064	1	0.172	1	0.064	1	0.779	1	0.173	1	0.671
Female	1.0 (0.6–1.7)		0.5 (0.3–1.0)		1.5 (0.8–2.7)		0.5 (0.3–1.0)		0.9 (0.4–2.2)		0.6 (0.3–1.2)		0.9 (0.5–1.6)	
Disability														
Independent	1	0.024	1	0.244	1	0.549	1	0.244	1	0.688	1		1	0.095
Mild disability	0.5 (0.2–0.9)		1.6 (0.7–3.5)		0.7 (0.3–1.4)		1.6 (0.7–3.4)		0.7 (0.2–2.0)		0.7 (0.3–1.6)		0.4 (0.2–1.0)	
Mod/severe disability	0.4 (0.2–1.0)		2.3 (0.8–6.7)		1.0 (0.3–2.7)		2.3 (0.8–6.7)		0.4 (0.0–4.6)		1.7 (0.6–4.9)		0.9 (0.3–2.5)	
Country														
England	1	0.018	1	<0.001	1	<0.001	1	<0.001	1	<0.001	1	<0.001	1	<0.001
France	1.9 (0.8–4.2)		7.4 (2.5–21.2)		24.4 (9.2–75.9)		7.4 (2.6–21.2)		45.0 (5.5–369)		19.4 (6.7–55.6)		19.9 (7.6–52.5)	
Germany	0.5 (0.2–1.1)		0.5 (0.1–2.6)		5.0 (1.7–14.7)		0.5 (0.1–2.6)		3.8 (0.4–40.0)		0.7 (0.2–2.3)		1.0 (0.4–2.6)	
Italy	1.0 (0.5–2.3)		14.9 (4.2–53.3)		14.8 (4.4–49.3)		4.7 (1.5–14.1)		3.0 (0.3–31.1)		1.6 (0.5–4.5)		3.8 (1.3–11.1)	
Scotland	0.8 (0.3–2.3)		4.7 (1.5–14.1)		4.7 (1.7–13.0)		14.9 (4.2–53.3)				5.1 (1.5–17.4)		0.6 (2.3–1.5)	

more likely to express interest to be involved, as were those with the highest level of education. Comparing those who were interested with those who were not, the former were more likely to be research aware (for example, reporting receiving the results of the register research they take part in, aware of research into stroke care and of clinical guidelines for stroke). They were also more likely to report taking part in register research in response to invitation from a clinician or stroke patient association, to have had opportunities to learn about research from a professional and to be told about research by a doctor during the course of a clinical consultation (Table 3).

Multivariable analysis

In multivariable analyses (Table 4), age was significantly associated with all questionnaire items, apart from whether or not the respondent found stroke register questions relevant to them. Older respondents were the least likely to report having opportunities to learn about stroke research from health professionals, hearing about research on patient care, being told about stroke research by their doctor, using information from the internet to discuss with a doctor, being aware of clinical guidelines or interested in getting involved in stroke research. The most severely disabled respondents felt the questions asked by the register were less relevant to them than those who were independent, but no other significant differences were observed by level of disability or gender. Significant differences between countries observed in univariable analyses were all also seen in the multivariable models.

Discussion

This study investigated stroke survivors' experience of research participation, research awareness and interest in becoming involved in research processes.

All respondents to this survey were already taking part in research by virtue of their participation in a stroke register. Yet, a relatively high proportion reported being unaware that they were taking part in research. All registers in this study have local ethics committee approval which required that informed consent was obtained from participants, although there is some evidence that the idea of informed consent itself may not be fully understood.[31] Lack of awareness may reflect the nature of register research itself, which is observational rather than interventional. Register data collection consists of asking participants about their current health status, stroke-related consequences, lifestyle and use of services. In some registers, this also includes monitoring of blood pressure. Anecdotally, we are aware that some participants regard the register follow-up interview as a form of 'health check' provided by the health service suggesting that the notion of therapeutic misconception may also apply to epidemiological research.[32]

Commonly cited reasons for research participation include both altruism and expectation of personal benefit.[33] In this study, the most commonly reported reason for taking part in a research register was in response to a request from a healthcare professional. This is not surprising as the registers through which these survey responders were contacted normally recruit participants as soon as possible after stroke and usually when patients are still in hospital. This interpretation is confirmed by comparison with respondents from the Swedish sample, where participants are recruited 3 months after stroke onset, and once discharged home or to another setting. Only 18% of Swedish participants selected 'request from a HCP' as their reason for taking part in Riks-Stroke.

Overall, research awareness among respondents appeared to be limited, both in terms of actively seeking out information about stroke research and being told about research evidence from healthcare professionals. This may not be specific to this patient population, as presumed low levels of patient and public awareness of clinical research have long been seen as a barrier to recruitment.[34] Contemporary concerns to increase recruitment have led

to the proposal of different strategies to raise research awareness targeting different sectors of the population.[35,36]

Most respondents reported that they had not used research results from any source during their consultations with a doctor. Although one European study reported an increase in the number of people using the internet to prepare for a medical consultation,[37] studies in other settings have reported that, perhaps contrary to expectations, few patients use internet health information when they visit the doctor.[38] For example, one American study of people aged 18–64 with health insurance found that 40% of participants had ever used information sourced from the internet in their consultations with doctors and that few understood the concept of evidence based care.[25]

Patient and public involvement in research processes is promoted as a citizen's democratic right, yet in this study, only 33% thought that patients themselves should make decisions about research. The one-third of participants who reported being interested in taking on a role in research processes appeared to be a distinct group in terms of age and educational level. The finding that stroke survivors aged <65 years were more interested in taking on such a role suggests a possible demographic shift in expectations about the engagement of citizens in the production of scientific knowledge. However, those who were interested in being involved in research processes also appeared to be already more research aware, reporting that information about research findings had been communicated to them by professionals. This may raise a question that has been the subject of some debate related to the representativeness of those who are engaged,[39] and the extent to which this matters. It has also been reported that patients' willingness to participate in shared decision making may differ by characteristics including age, gender, disease type and severity and ethnicity.[40,41] While the category of 'patient' is undifferentiated in policy led calls for increased patient involvement at all levels, individuals' desire and capacity to be involved may differ.

This was an exploratory study investigating stroke patient awareness and use of research. Using a survey was a pragmatic choice, but we acknowledge that this is a fairly blunt instrument with which to explore complex issues. We used an appropriate strategy to design and test the questionnaire, including use of existing questions from a previously published study and working with members of the target population. A good response rate was achieved but those with more severe disabilities may be under-represented. The Swedish sample differs from the rest of total sample as demographic and outcome data were not available, and given the stipulation that participants should complete the questionnaire unassisted, this is likely to be a less disabled group.

Recruiting from existing population stroke registers was a strength as such registers have lower risk of participant bias. However, as participants were already taking part in research, they might be expected to be more research aware than those not taking part in research. Nevertheless, it may well be that for some participants, it was unclear that taking part in a register collecting observational data, constitutes taking part in research.

There were important differences in response by country with respondents from France showing higher levels of research awareness and those from England and Italy showing lower levels. However, further research would be needed to replicate and understand these findings.

Conclusion

This survey investigated stroke survivors' awareness of and attitudes towards research. We found low levels of research awareness and use of research evidence in consultations between patients and their doctors. Although research seemed to be regarded largely as within the competence of professionals, around one-third of respondents reported an interest in becoming involved in research processes. Yet, these were atypical of the stroke population, not only younger and more highly educated but already research aware.

As far as stroke survivors in Europe are concerned, the patient revolution that engagement has been said to herald may require some ground work.[3] Our findings suggest a need for greater efforts to raise awareness of how patient involvement in identifying and using research evidence can lead to increased quality of care for individuals and populations. Efforts to communicate research findings to patient populations could be undertaken at the level of individual patient; by researchers increasing their communication of study findings to participants; and increased engagement in research dissemination by patient associations. Some such organizations are already active in raising funds for research but they, along with researchers, funders and health services need to consider more actively encouraging awareness of the research cycle from the production of evidence to its implementation in routine care, as well as the parts that patients themselves might play in these processes.

Acknowledgements

This paper was written on behalf of the European Implementation Score (EIS) project, funded by the EU 7th Framework Programme. This is a collaboration between King's College London, University of Florence, University of Lund, London School of Economics, University College London, the German Stroke Foundation and Charité – Universitätsmedizin Berlin. The work packages are led by: Prof. C. Wolfe, Prof. D Inzitari, Dr J. Baeza, Prof. B. Norrving, Prof. P. Heuschmann, Prof. A. McGuire, Prof. H. Hemingway, Dr M. Wagner and Prof. C. McKevitt. Contribution to data collection for this study was additionally provided by Professor Peter Langhorne, Academic Section of Geriatric Medicine, Royal Infirmary, Glasgow, United Kingdom and Professor Kjell Apslund Department of Medicine, University Hospital, Umeå, Sweden. CM, NF, SN and CDAW acknowledge the support of the National Institute for Health Research (NIHR) Biomedical Research Centre based at Guy's and St Thomas' NHS Foundation Trust and King's College London. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Information on the stroke registers.

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